

Colleen Lanier Christensen

As a member of the Associate Board of the Illinois Maternal and Child Health Coalition (IMCHC), thank you for the opportunity to comment on the Illinois Navigator Program Design Final Report. IMCHC is a statewide, nonprofit organization that focuses on the promotion and improvement of health outcomes for women, children, and their families through advocacy, education, and community empowerment. For nearly 25 years, we have fought for affordable, high-quality health care, and have a strong interest in ensuring that Illinois residents have every available opportunity to benefit from full implementation of the Affordable Care Act (ACA) in Illinois. For over seven years, IMCHC served as the lead organization for Covering Kids and Families Illinois, which was part of a nationwide initiative to enroll eligible children and parents into public coverage programs. IMCHC also played a strong role in outreach and enrollment efforts for All Kids, when the program was first announced in 2006 and when the expansion took effect in 2007. We have also been a strong advocate on behalf of the All Kids Application Agent (AKKA) program, which has shown to be extremely effective in outreach and enrollment efforts, and are pleased to see AKKAs included in the final report as a model program on which an Illinois Navigator program should be built upon. As a result, IMCHC is extremely disappointed by the decision to eliminate funding of the Technical Assistance Payments (TAP) to AKKAs, effective July 1, 2012, as a result of the Medicaid cost-reductions. Illinois has benefited greatly from the AKKAs enrollment and outreach, most recently illustrated through three consecutive years of “bonus payments” amounting to close to \$40 million. Illinois received these payments for meeting enrollment goals set forth by the federal Children’s Health Insurance Reauthorization Act. As noted below, a single year of these bonuses could easily fund numerous Navigator grants. IMCHC strongly encourages reinstating AKAA funding and using these bonuses to help support a robust Navigator program. It’s estimated that over 1.6 million Illinois residents will benefit from full implementation of the ACA in 2014, through the establishment of a Health Insurance Exchange and the Medicaid expansion. While the Exchange is expected to streamline the application process for Medicaid and tax credits for private insurance, it is expected that many individuals will still require personalized assistance to understand their options for coverage and submit an application. Given Illinois’ recent decision to pursue a state-federal partnership Health Insurance Exchange in 2014, we urge state officials to work closely with the federal government to retain full oversight and control of the Navigator program. This will ensure that Illinois has full operational powers to create and run a Navigator program and ensure a smooth transition once a state-based Exchange goes into effect in 2015. Overall, IMCHC agrees with nearly all of the proposed recommendations and stakeholder findings in the Navigator Final Report. Specifically, we insist that following findings must be

Navigator Program Comments

*Comments appear exactly as submitted

included in Illinois' Navigator program in order to ensure successful outreach and enrollment:

- Navigator grants must be awarded through a competitive RFP process that allows for organizations throughout Illinois to apply and offer their unique approaches to outreach and enrollment for consideration.
- Conflict of interest provisions must be developed in a manner that ensures the utmost program integrity and assurance that Navigators are working in the best interest of consumers. Strong oversight and quality measures should must also be developed. Feedback from individuals who utilize Navigator services should be incorporated into this process and consumers should be informed of the formal grievance/complaints process.
- Ongoing input from stakeholders is a critical part to the development and implementation of a Navigator program. Regular meetings, at least every other month, should take place leading up to the launch of the program, and through the 12-18 months. Additionally, IMCHC offers the following recommendations:
- Illinois should conduct a "needs assessment" in order to better understand where persons who will benefit from Navigator services reside. This needs assessment will help target limited resources and help the state better craft an RFP that best addresses outreach and enrollment needs.
- Block grant funding with a pay-for-performance bonus may be an appropriate approach to funding Navigators. However, this model of funding should be reviewed 18-24 months after the awarding of the first grant to determine whether or not this payment mechanism should be revised.
- While the efforts of Navigators should be focused on outreach and enrollment for the individual market, especially in the first few months of operation, we think that the door for Navigators to assist with enrollment into SHOP should be kept as an available option, as Navigators may be useful towards these efforts in the future.
- Navigators should be viewed as a "feedback mechanism" for the state, in order to help monitor the efficacy of the Exchange and towards broad-based outreach efforts. To this end, Navigators should be required to meet on a regular basis with state officials to share this feedback. These meetings should occur more frequently when the grants are first issued in 2013 and then occur at a minimum annually after the first 12-24 months.
- We strongly suggest that the Illinois' Navigator program include additional training for Navigators to screen and refer for other public benefit programs. Given the integrated eligibility system that the Illinois Department of Healthcare and Family Services (HFS) is in the process of building, giving Navigators the resources and basic information about these programs can help connect more eligible individuals to these programs.
- In order to ensure quality performance and program integrity, we suggest that recertification take place more frequently in the first two years of operation of the Navigator program. We also think that the initial Navigator training should be mandatory to attend in person to ensure the maximum level of participation and engagement by the individual who will be conducting enrollment and outreach.
- We

Navigator Program Comments

*Comments appear exactly as submitted

agree that data should be provided to Navigators on a monthly basis and support the development of an online portal where Navigators can submit reports and data that they must provide as part of their grant agreement. We also think that information about the Navigator program, including progress towards the overall program goals should be reported about the Exchange on a regular basis, perhaps on the Exchange website, as well as included in any reports that the Exchange issues to the public. •In response to funding mechanisms, Illinois should consider using money awarded from CHIPRA bonus payments towards the initial “seed” funding for Navigator grants. Illinois received consecutive performance bonuses for meeting enrollment goals in our Medicaid and Children’s Health Insurance Programs for the past three years. The total amount awarded over the last three years has been close to \$40 million. However, with the elimination of the AKA \$50 Technical Assistance Payment (TAP) in FY13, it is much less likely that Illinois will be awarded this bonus again. Given that Illinois’ share of the TAP is estimated to be \$425,000 in FY13, it would be worth reinstating the TAP to give Illinois the opportunity to qualify for this bonus. Based on the bonus that Illinois was awarded in 2012 and HMA’s “high-end estimates” for Navigator budgets, we could easily fund the entire first year of the program with a single CHIPRA bonus payment. While we agree that AKAs should be encouraged to apply to serve as Navigators, it is unclear at this point whether full integration of the AKAs, to the point where there would no longer be agencies that only assisted with All Kids applications, is necessary or helpful to outreach efforts. And while the following comment may be outside of the scope of this report, HFS should consider opportunities to use administrative data and information that is already available through other state databases and information systems in order to “auto-enroll” eligible individuals when possible into Medicaid. Given, that it is estimated that over 600,000 people will be newly eligible for Medicaid in 2014, utilizing existing data sources can save time and money. We hope that you will continue to use IMCHC as a resource on this issue. If you have additional questions, please contact Kathy Chan, IMCHC’s Director of Policy and Advocacy at 312-491-8161x24 or at kchan@ilmaternal.org. Thank you again for the opportunity to comment.

William R. McAndrew

On behalf of the Illinois Hospital Association (IHA) and its 200 member hospitals, we are pleased to provide comments on the Illinois Navigator Program Design Final Report (the Report). Illinois hospitals often serve as the first point of interaction with the health care delivery system for the uninsured and underinsured in Illinois. IHA has been following discussions relating to the navigator program very closely, and we appreciate the time and effort put into writing this Report. There are many parts of the

Navigator Program Comments

*Comments appear exactly as submitted

Report that IHA supports. We agree that Navigators should not, at the outset, be expected to perform Small Business Health Options Program (SHOP) enrollment functions under the Health Benefits Exchange and that Illinois should fully integrate the All Kids Application Agents (AKAA) and Navigator programs (both recommendations are contained in Section IX. Recommended Navigator Model). IHA also agrees with stakeholder comments that hospitals be allowed to participate as Navigators where appropriate. In general, IHA has consistently supported a fully functioning state Exchange. In so doing, we have argued that the state ensure, as much as possible, that the Exchange not over reach in establishing the minimum operating requirements to ensure full participation. We have also consistently argued for ensuring that disruptions to existing commercial insurance markets are held to a minimum. Our comments below reflect these concerns.

Section VI. Navigator Program Design

a. The Report recommends that Illinois consider giving Navigators responsibility for follow-up and on-going assistance to clients. While IHA does not oppose such duties where appropriate, there may be many situations in which follow-up is impossible, particularly when dealing with clients who are transient or clients who find a more preferred navigator in their community. IHA recommends that while follow-up duties are recommended, they not be required and reimbursement should not be withheld when follow-up is not appropriate.

b. The Report also recommends prohibiting grants to individuals acting as Navigators, instead relying on entities to hire appropriate individuals to perform the required Navigator duties. While IHA understands the increased administrative and oversight responsibility that the state would assume by providing grants to individual Navigators, there may be instances in some communities where entity involvement is not practical. IHA recommends that while the entity-based model suggested by the Report be the predominant model, exceptions should be made to allow individuals to participate as Navigators when necessary to reach target populations.

c. The Report recommends Navigators be selected through a request-for-proposal (RFP) process, with an initial and possibly a secondary RFP. Not only would such a process seem to exceed the requirements currently in place for insurance producers (a more highly regulated profession), but it would also likely act as a severe barrier to entities and individuals to participate. Any program recommendation which could adversely affect participation in the Navigator program, and thus the enrollment process, should be avoided. IHA understands that the process needs to be more regulated than that for the AKAA, but there are ways to build on the AKAA process to allow easier participation while establishing appropriate oversight for the Navigator program. In addition, the Navigator certification process should follow the “rolling admissions” process similar to that of AKAA in order to ensure a sufficient Navigator workforce. Proof of minimum qualifications could be required at time of certification and annual renewal as with insurance producers.

d. The Report

Navigator Program Comments

*Comments appear exactly as submitted

recommends an annual retraining process. Such a requirement would exceed requirements applicable to insurance producers. In fact, once a Navigator is trained and enrolling individuals on a regular basis, retraining would act as a barrier to those wishing to participate. IHA recommends the Report's alternative proposal of establishing a continuing education component with proof of completion, due annually at renewal, as with insurance producers. VII. Navigator Compensation Structure a. The report recommends Navigator reimbursement rely solely on a block-grant structure with various types of add-on payments to reward good performance. IHA does not oppose this structure, but consistent with comments above, we recommend an additional layer of compensation be established, roughly mirroring the AKAA program, for grants to individuals acting as grant recipient Navigators. While the current AKAA reimbursement methodology may be too low for the Navigator program, a similar type of reimbursement structure to AKAA, with the anticipation of add-on payments for good performance, could be established. Thank you for the opportunity to comment on this Report.

Lillian Johnston

To whom it may concern: I am a resident of Illinois who has a family member diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop

Navigator Program Comments

*Comments appear exactly as submitted

serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Moriel McClerklin

I want to commend the committee for its recommendations. There are two areas of concern for our constituency. First, the scope of services proposed for the navigator organizations is too broad. Some of the proposed services places the navigator into the role of an insurance broker, which leads to liability issues for the navigator. We believe that the role of insurance broker should be continued by insurance agency, while the navigator assumes an education role. Secondly, the amount of funding proposed for the navigator organizations is too small for navigators to successfully fulfill their role.

Marilyn Walker

To whom it may concern: I am a resident of Illinois who is diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy

Navigator Program Comments

*Comments appear exactly as submitted

and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions (such as Common Variable Immunodeficiency-with no memory Cell), in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all! Thank you for your efforts, Marilyn Walker 624 W. McDonough St. Macomb, IL 61455

Patricia A Johnson

To whom it may concern: I am a 63 year old tax paying resident of Illinois who is diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality

Navigator Program Comments

*Comments appear exactly as submitted

health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. PLEASE DO NOT JEOPARDIZE MY HEALTH FOR LACK OF KNOWLEDGE.

Christine Warner

To whom it may concern: I am a resident of Illinois who has a family member / friend diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Dennis P Rosenbaum

To whom it may concern: I am a resident of Illinois who has a family member / friend diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all! Thank you for your attention to this request.

Kim DiGangi

To whom it may concern: I am a resident of Illinois who is diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD).

Navigator Program Comments

*Comments appear exactly as submitted

Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Louis Ressler

To whom it may concern: I am a resident of Illinois who is diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In

Navigator Program Comments

*Comments appear exactly as submitted

addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all! Thank you for your efforts.

David Bond

Please establish a Navigator program!

Pamela N. McQuillen

To whom it may concern: I am a resident of Illinois who is diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs

Navigator Program Comments

*Comments appear exactly as submitted

through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Shira Saliman

It's estimated that over 1.6 million Illinois residents will benefit from full implementation of the ACA in 2014, through the establishment of a Health Insurance Exchange and the Medicaid expansion. While the Exchange is expected to streamline the application process for Medicaid and tax credits for private insurance, it is expected that many individuals will still require personalized assistance to understand their options for coverage and submit an application. Given Illinois' recent decision to pursue a state-federal partnership Health Insurance Exchange in 2014, I urge state officials to work closely with the federal government to retain full oversight and control of the Navigator program. This will ensure that Illinois has full operational powers to create and run a Navigator program and ensure a smooth transition once a state-based Exchange goes into effect in 2015. Overall, I agree with nearly all of the proposed recommendations and stakeholder findings in the Navigator Final Report. Specifically, I insist that following findings must be included in Illinois' Navigator program in order to ensure successful outreach and enrollment:

- Navigator grants must be awarded through a competitive RFP process that allows for organizations throughout Illinois to apply and offer their unique approaches to outreach and enrollment for consideration.
- Conflict of interest provisions must be developed in a manner that ensures the utmost program integrity and assurance that Navigators are working in the best interest of consumers. Strong oversight and quality measures should must also be developed. Feedback from individuals who utilize Navigator services should be incorporated into this process and consumers should be informed of the formal grievance/complaints process.
- Ongoing input from stakeholders is a critical part to the development and implementation of a Navigator program. Regular meetings, at least

Navigator Program Comments

*Comments appear exactly as submitted

every other month, should take place leading up to the launch of the program, and through the 12-18 months. Additionally, I offer the following recommendations:

- Illinois should conduct a “needs assessment” in order to better understand where persons who will benefit from Navigator services reside. This needs assessment will help target limited resources and help the state better craft an RFP that best addresses outreach and enrollment needs.
- Block grant funding with a pay-for-performance bonus may be an appropriate approach to funding Navigators. However, this model of funding should be reviewed 18-24 months after the awarding of the first grant to determine whether or not this payment mechanism should be revised.
- While the efforts of Navigators should be focused on outreach and enrollment for the individual market, especially in the first few months of operation, I think that the door for Navigators to assist with enrollment into SHOP should be kept as an available option, as Navigators may be useful towards these efforts in the future.
- Navigators should be viewed as a “feedback mechanism” for the state, in order to help monitor the efficacy of the Exchange and towards broad-based outreach efforts. To this end, Navigators should be required to meet on a regular basis with state officials to share this feedback. These meetings should occur more frequently when the grants are first issued in 2013 and then occur at a minimum annually after the first 12-24 months.
- I strongly suggest that the Illinois’ Navigator program include additional training for Navigators to screen and refer for other public benefit programs. Given the integrated eligibility system that the Illinois Department of Healthcare and Family Services (HFS) is in the process of building, giving Navigators the resources and basic information about these programs can help connect more eligible individuals to these programs.
- In order to ensure quality performance and program integrity, I suggest that recertification take place more frequently in the first two years of operation of the Navigator program. I also think that the initial Navigator training should be mandatory to attend in person to ensure the maximum level of participation and engagement by the individual who will be conducting enrollment and outreach.
- I agree that data should be provided to Navigators on a monthly basis and support the development of an online portal where Navigators can submit reports and data that they must provide as part of their grant agreement. I also think that information about the Navigator program, including progress towards the overall program goals should be reported about the Exchange on a regular basis, perhaps on the Exchange website, as well as included in any reports that the Exchange issues to the public.
- In response to funding mechanisms, Illinois should consider using money awarded from CHIPRA bonus payments towards the initial “seed” funding for Navigator grants. Illinois received consecutive performance bonuses for meeting enrollment goals in our Medicaid and Children’s Health Insurance Programs for the past three years. The total amount awarded over the last three years has been close to

Navigator Program Comments

*Comments appear exactly as submitted

\$40 million. However, with the elimination of the AKAA \$50 Technical Assistance Payment (TAP) in FY13, it is much less likely that Illinois will be awarded this bonus again. Given that Illinois' share of the TAP is estimated to be \$425,000 in FY13, it would be worth reinstating the TAP to give Illinois the opportunity to qualify for this bonus. Based on the bonus that Illinois was awarded in 2012 and HMA's "high-end estimates" for Navigator budgets, I could easily fund the entire first year of the program with a single CHIPRA bonus payment. While I agree that AKAAAs should be encouraged to apply to serve as Navigators, it is unclear at this point whether full integration of the AKAAAs, to the point where there would no longer be agencies that only assisted with All Kids applications, is necessary or helpful to outreach efforts. And while the following comment may be outside of the scope of this report, HFS should consider opportunities to use administrative data and information that is already available through other state databases and information systems in order to "auto-enroll" eligible individuals when possible into Medicaid. Given, that it is estimated that over 600,000 people will be newly eligible for Medicaid in 2014, utilizing existing data sources can save time and money.

Charles Darwall

Dear Members of the Council. I am a resident of Illinois, living in Evanston. I have a rare genetic (inherited) condition that has resulted in serious, chronic lung disease. This life threatening condition requires me to take medication costing in excess of \$80,000 a year for the rest of my life. I am the breadwinner for my family, and have a son with special needs. In the development of the Illinois State Exchange, please take into consideration and account for those patients who suffer from rare and chronic diseases. These individuals present unique challenges within the health care system, as many rare diseases require expensive, complex and specialized treatments. Please make sure that the state navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with information to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, and adequately represent the populations that are most likely to enroll in the Exchange.

Linda B. Olson

To whom it may concern: I am a resident of IL who has a child diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic disease, such as those with primary immunodeficiency diseases.

Navigator Program Comments

*Comments appear exactly as submitted

(PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and any disruptions in care can have devastating effects. Specifically, patients with PIDD require access to LIFE-SAVING INTRAVENOUS IMMUNOGLOBULIN (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatments. Patients of QHPs should not be limited in their choice of therapies because of the importance of PIDD patients accessing the product that best meets their clinical needs. PATIENTS THAT RECEIVE THEIR IMMUNOGLOBULIN REPLACEMENT TREATMENT CAN LIVE NORMAL, HEALTHY AND PRODUCTIVE LIVES. Without treatment, patients with primary immunodeficiency disease will become increasingly sicker, utilize the healthcare system constantly, and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate info that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted

Kimberley Larsen

To whom it may concern: I am a resident of Illinois who has two little boys diagnosed with a primary immunodeficiency disease, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-saving intravenous immunoglobulin (IVIG) therapies on a monthly basis, such as my boys receive at Children's Memorial. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely

Navigator Program Comments

*Comments appear exactly as submitted

affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all!

Jean A Guenther

My adult daughter lives in Oak Park, Illinois, and has a primary immune deficiency. This is a rare, life-threatening, chronic disease. She currently is able to live independently, in part due to the expensive treatment she receives, as well as specialized care for her unique needs. It's crucial that she and others with rare and chronic conditions have information to make informed choices to best meet their serious health challenges. I feel the navigators must be trained, reliable, well-informed individuals who will be able to guide those who are the most medically challenged individuals in Illinois. My daughter's life is severely limited by her medical condition, and I appreciate her having the best quality of life possible. Thank you.

Emily Hovermale

To whom it may concern: I am a representative of the Immune Deficiency Foundation, the national patient organization for individuals diagnosed with primary immunodeficiency diseases, a rare and chronic genetic condition. The manner in which the Health Care Reform Implementation Council chooses to implement state-level Exchanges could have a critical impact on patients with rare and chronic diseases, such as those with primary immunodeficiency diseases (PIDD). Communication with individuals regarding their rights and protections is critical for the successful implementation of the Exchanges. Many patients with rare and chronic conditions rely on a regular treatment regimen, and disruptions in care can have devastating effects. Specifically, patients with PIDD require access to life-

Navigator Program Comments

*Comments appear exactly as submitted

saving intravenous immunoglobulin (IVIG) therapies on a monthly basis. All forms of IVIG are not the same, and without strong requirements regarding drug coverage, patients could be forced to switch from one form of IVIG to another, with the potential for serious adverse effects. In addition, such therapies are complex and expensive. Robust anti-discrimination standards are needed to ensure that patients are not adversely affected or denied critical treatments through administrative limitations on treatment. Patients of QHPs should not be limited in their choice of therapies under QHPs through formularies. It is important that IVIG not be included in any formulary because of the importance of PIDD patients accessing the product that best meets their individual clinical needs. Patients who are able to receive their immunoglobulin replacement treatment can live normal, healthy and productive lives. Without treatment, patients with primary immunodeficiency diseases will become increasingly sicker, utilized the health care system constantly and will develop serious and severe co-morbidities and disabilities. It is essential that the navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with appropriate information that reflects their rare and chronic condition to fully understand their quality health plan options. In addition, the navigators must have adequate training, be trusted sources of information, have no financial conflicts of interest and adequately represent the populations that are most likely to enroll in the Exchange. One size does not fit all! Thank you for consideration of this critical issue.

Russell John Welchert

I have Alpha 1 Antitrypsin deficiency. This is a rare genetic (inherited) condition that may result in serious, chronic lung and/or liver disease. In the development of the Illinois State Exchange, please take into consideration and account for those patients who suffer from rare and chronic diseases. These individuals present unique challenges within the health care system, as many rare diseases require expensive, complex and specialized treatments. Personally, I was diagnosed in 2005 and was given roughly 5 years to live. Immediately I began augmentation therapy to replace the antitrypsin. The therapy is working as my lung function has remained the same for the past 7 years. The therapy cost approximately 4k each week. I am unemployed and continue to receive medical insurance through my former company's COBRA plan. Without this therapy my life or quality of life is in jeopardy. Please feel free to contact me with any questions. Please make sure that the state navigators must understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with information to fully understand their QHP options. In addition, the navigators must have adequate training, be trusted sources of information, and adequately represent the populations that are most

Navigator Program Comments

*Comments appear exactly as submitted

likely to enroll in the Exchange.

Sarah Joyce

All of the duties that you are looking for Navigators to do, are functions currently provided by brokers in Illinois. Needless dollars would be spent and Employers and Employees stand nothing to gain and have an awful lot to lose.

Dragana Salom

Just a note for Governor's office:

All of the duties they are looking for Navigators to do, are functions currently provided by brokers in Illinois. Needless dollars would be spent and Employers and Employees stands nothing to gain and have an awful lot to lose. Thank you.

Brian Crane

All of the duties you are looking for Navigators to do, are functions currently provided by brokers in Illinois. Needless dollars would be spent and Employers and Employees stands nothing to gain and have an awful lot to lose. I hope you will review this a little bit more carefully.

Alan Levitz

The Navigator program is a colossal waste of taxpayer money, regardless of whether the money is from state or federal taxpayers. Currently there is a very informed, experienced group of agents and brokers within the state that can provide better assistance than a two month training program will provide. The Navigator Program will create yet another layer of bureaucracy that will provide little to no assistance to the majority of consumers.

Connie Boyd

Dear Governor-Please read my response. All the duties they are looking for Navigators to do, are functions currently provided by brokers in Illinois. Needless dollars would be spent and Employers and Employees stands nothing to gain and have an awful lot to lose. I hope you read my comment. It is important to me and to all. Thank you

Jeff Kolker

Navigator Program Comments

*Comments appear exactly as submitted

I have reviewed the services you are expecting a Navigator to perform and am very concerned about the caliber of person you will get to be a Navigator. Currently, I believe insurance agents are in the best position to act as Navigators to explain, enroll and educate the population on health care plans and options. Creating an entirely new model will be less efficient and much more costly.

Richard S. Levitz

Comment: With all due respect, all of the duties that the State is looking for Navigators to do, are functions currently provided by insurance brokers in the State of Illinois. Needless dollars wwill be spent on this program and Employers and Employees stand nothing to gain as they are already being well educated by licensed brokers and have an awful lot to lose, by Navigators replacing quality brokers. Thanks very much.

David Levitz

Everything the in report outlining the specific duties of a navigator is already being performed by the hundreds of brokers in Illinois. The navigator program would be an unnecessary expense and not provide nearly the expertise that the broker community is already providing. Our office gets hundreds of calls each month from clients (employers and employees) having issues with their carrier. Navigators would not be able to handle the volume of requests and more importantly would not offer the stability provided by brokers.
